

Cancer survivors and the patient-centered medical home

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Abstract

Survivor care plans have been described as useful tools for enhancing the quality of follow-up care that cancer survivors receive after their active treatment has been completed. The relative success of current survivor care plan models is strongly dependent on the actions of individual patients. In this qualitative study of 33 cancer survivors, we explored patients' understanding of follow-up care and their motivations and resources for seeking care. Three types of survivor experiences were identified from narratives of patients treated in community oncology and National Cancer Institute-designated comprehensive cancer centers, ranging from nonactivated patients who need enhanced health care communication and decision support to navigate their care to highly activated patients adept at navigating complex health care settings. Using the patient-centered medical home as a conceptual framework, we propose a research, policy, and practice agenda that advocates for multifaceted decision support to enhance cancer survivorship and follow-up care.

KEYWORDS

Cancer survivors, Patient-centered medical home, Qualitative research, Cancer survivorship, Cancer follow-up

BACKGROUND

In January 2008, the number of cancer survivors in the USA was estimated as 11.9 million [1]. By 2050, the estimated number of cancer survivors will surpass new cancer cases, putting greater demand on service providers and systems of care. More than half of individuals already diagnosed with cancer are expected to survive for more than 5 years. Forty percent of women survivors are diagnosed with breast cancer and 41 % of men survivors received prostate cancer diagnoses [2]. For common tumors such as breast and prostate, 5-year survival exceeds 90 % [3]. Survivors of these cancers have a high prevalence of health-related problems resulting from cancer treatment in addition to concerns about second cancers.

Approximately 70 % of cancer patients have comorbid conditions that require a comprehensive approach to medical care [4, 5]. Cancer survivors experience a number of challenges associated with

Implications

Practice: Cancer survivorship care that utilizes a patient-centered medical home (PCMH) framework recognizes that patients are not monolithic and that not all patients have equivalent or comparable capacity to act as their own advocates.

Policy: Health and behavioral care clinicians need to attend to the diverse range of patient experiences and expectations of follow-up care, and PCHM approaches to survivorship care need to be multifaceted to address the multiple and complex needs of cancer survivors.

Research: Given that current models of the PCMH and cancer survivorship care rely heavily on highly activated patients to ensure successful outcomes, further research is needed to understand how best to enhance patient knowledge, engagement, and activation.

their cancer diagnoses and subsequent treatment including progressive disease [6–8], comorbid conditions [6, 8], functional decline [6, 8], and premature death [6]. Both breast and prostate cancer survivor populations have reported sexual problems [7, 9] and varying levels of psychosocial distress [2]. Breast cancer survivors are at increased risk for metabolic disorders including obesity, cardiovascular disease, and osteoporosis as late effects related to treatment [8]. Prostate survivors face osteopenia [8], radiation proctitis [9], incontinence [9–12], impotence [9–12], and a host of other health problems related to treatment [9–12]. In addition, new data suggest that over 60 % of survivors will be 65 years or older by the year 2020 [1] with multiple morbid conditions that require a comprehensive approach to care management.

Cancer survivors require long-term or “extended” cancer follow-up care after the end of their active cancer treatment. Survivor follow-up management entails more than routine surveillance for recurrence of cancer [13, 14]. It also requires proactive care, which includes systematic planning for cancer prevention and surveillance that is patient-centered. Patient-centered care includes delivery of care that takes into account the survivor's personal risk of cancer recurrence or development of a new cancer

site, their previous and/or current cancer therapies, their genetic predispositions, their lifestyle and health-related behaviors, as well as other comorbid health conditions [13, 15, 16]. Because of their complex comorbid status and need to deal with cancer as a chronic illness, cancer survivors need a patient-centered medical home (PCMH).

The PCMH has been proposed by a number of physician organizations (e.g., American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, and American Osteopathic Association) as a promising new model of primary care as it focuses on providing care for the whole patient [17–19]. It combines “high-tech” improvements to care such as using an electronic medical record to achieve better documentation and coordination of care; using registries to promote population-based disease management; and redesigning practice cultures and processes to improve quality, lower costs, and raise patients’ satisfaction [17, 20]. It also espouses a “high-touch” approach to providing care that is whole person-oriented and cultivates relationships between patients and their health care team, which is led by a personal physician who is trained to provide a first point of contact and to coordinate continuous and comprehensive care [17, 18]. The concept of PCMH promotes team-based care that enhances roles and responsibilities within the entire primary care practice and also emphasizes active outreach to and engagement of patients, even outside of the primary care practice site [20].

In 2011, the National Committee for Quality Assurance (NCQA), which accredits US health plans and tracks statistics for quality of care delivered by them, took up the challenge of improving primary care by advocating for PCMHs. NCQA established a core set of six PCMH standards and measurement elements, based on the founding PCMH principles [21]. The goal was to provide objective measures for documenting the extent to which practices and providers achieve PCMH goals of organizing care around patients, working in teams, and coordinating and tracking care over time. Four, in particular, are worth noting as specifically relevant for cancer survivors: (no. 2) identifying and managing patient populations and using data for population management; (no. 3) planning and managing care through care management; (no. 4) providing self-care and community support which includes supporting the self-care process; and (no. 5) tracking and coordinating care through referrals and follow-up. Yet, to gain the most benefit from the PCMH, whatever the disease focus, “activated patients” are required [22]. Activated patients are patients that are engaged in their care [23–25] and who can manage their care in complex settings and have the skills and tools to function in a decision-making role [26, 27]. Indeed, many of the cancer survivorship models of care [16, 28–30] and survivorship care planning [28, 30–32] literatures place the cancer patient at the center of his/her care circle and require a high level of patient engagement to achieve

even minimal care management and coordination. To be sure, there are components of the PCMH philosophy that can be implemented at a practice level, which may help to facilitate care of less activated patients, such as identifying and managing cancer survivors at the population level, providing care management, and tracking/coordinating their care. However, many of these strategies have yet to be implemented in a comprehensive or systematic fashion, leaving cancer survivors largely responsible for coordinating their own care. It is unclear that the majority of survivors have the necessary knowledge and tools required to adequately advocate and navigate both complex systems of care, as well as advocate effectively for themselves. There are no studies that examine the care of cancer survivors within a PCMH context. In this paper, we present experiences of cancer survivors seeking follow-up care to further inform discussions and conceptualization of the PCMH and the nature of its role in facilitating continued health care seeking behaviors of cancer survivors.

METHODS

Setting

In March–October 2009, we conducted an exploratory qualitative study that recruited cancer survivors in New Jersey who had received their cancer treatment from one of five community hospitals (AtlantiCare–The Cancer Care Institute, Somerset Medical Center, South Jersey Healthcare, UMDNJ–The University Hospital, and Virtua Fox Chase Cancer Program) or from two National Cancer Institute (NCI)-designated comprehensive cancer centers (The Cancer Institute of New Jersey and Fox Chase Cancer Center). These institutions were chosen to represent the diversity of the region’s cancer treatment facilities (i.e., community hospitals, teaching hospitals, NCI-designated comprehensive cancer centers). This study was approved by the institutional review boards at UMDNJ and FCCC, as well as by the five community hospitals.

Sampling frame

We recruited a purposive sample of ambulatory, early stage (I or II) breast and prostate cancer survivors for whom the Institute of Medicine authors recommend longitudinal survivorship health care (i.e., defined as ≥ 2 years from completion of cancer therapy other than hormonal therapy). Patients with severe comorbid conditions that require extensive specialist care coordination (e.g., congestive heart failure, myocardial infarction, angina) were excluded. The sample of patients was stratified according to (1) number of years from treatment (<5 , 6–9, 10+) and (2) location of cancer treatment (community hospital versus cancer center). Additionally, we oversampled African-Americans and recruited an age-representative sample of New Jersey cancer survivors (i.e., half over the age of 65 years).

Data collection

In-depth, individual interviews were conducted in English by telephone (95 %) or in person (5 %) according to the participants' preference. Survivors were referred to the study through their cancer treatment facilities. Study investigators worked with staff in the clinical research offices of the cancer centers and hospitals, the survivor clinics, and the individual clinicians to identify eligible patients. Potential participants were mailed a letter from the principal investigator (SVH) that introduced and explained the study and contained information about their rights under the Health Insurance Portability and Accountability Act and two informed consent forms with a return envelope. Follow-up phone calls were initiated approximately 3–5 days after mailings were sent to gauge study interest. Those interested in participating were asked to return one signed copy of the documentation and scheduled for interviews. Participants received a \$35 American Express gift card for completing the interview.

Interviews ranged from 30 to 90 minutes and were conducted by masters-prepared interviewers with extensive qualitative interviewing experience. A semi-structured interview script was developed to elicit information about the transition of survivors out of active cancer treatment, focusing on their understanding of who was providing their cancer follow-up care and their satisfaction with the quality of the follow-up care they had received (for the published interview guide, see Hudson et al. [33]). The interview guide did not explicitly ask patients about the PCMH; however, it did address concepts of the PCMH such as relationship with their personal physicians, the role of primary care in their follow-up, and the extent to which their follow-up care is coordinated between their oncology treatment and primary care health teams, as well as their perceptions of care quality and access to care.

Sixty-two patients were invited to participate in the study; 24 breast cancer and 18 prostate cancer survivors completed interviews for a participation rate of 67 % (for the demographics, see Table 1). Interviews were digitally recorded and transcribed. In addition, interviewers provided field notes for each interview. Recordings from two interviews were inaudible and the interviews from an additional seven individuals did not contain adequate data for a paired analysis of their understandings of follow-up care and their levels of involvement or active engagement in their care; therefore, they were excluded from the current analysis. Data from the remaining 33 interview transcripts served as the data source for this analysis.

Coding, analysis, and typology construction

Our qualitative analysis used a multistep immersion/crystallization approach [34]. This approach consisted of an iterative process that included cycles of reading, summarizing, and rereading the data [34–36]. Sections of text were reviewed by two

sociologists and a bachelors-prepared biology major/public health minor (SVH, JH, and AM). From the first cycle of transcript reviews, a series of distinct characteristics began to emerge from the data. We began to see common sets of characteristics and conditions experienced by patients that suggested that constructing typologies would be useful for understanding their follow-up care experiences (see Table 2). Patients' were grouped together based on their understanding of follow-up care and their levels of involvement or active engagement in their care. Once we were clear about the concepts, we conducted a second, more focused round of reading and summarizing the transcripts. JH and AM then separately and independently read through the data and applied codes to segments of the transcripts. The analysis team met weekly to discuss data analysis and interpretation. Differences in interpretation of the data between JH and AM were resolved through discussion. For coded text where there was discrepancy between coders, determination of final code assignment was achieved through discussion and group consensus; we, therefore, achieved 100 % agreement in terms of inter-rater reliability for coded text segments used to construct our group summaries. We used ATLAS.ti [37] software to facilitate our qualitative analyses and IBM SPSS® version 19 to complete the descriptive analyses.

RESULTS

The median age of the participants was 64.2 years and 49 % were women. Self-reported race and ethnicity were 67 % non-Hispanic White and 33 % Black. Blacks were overrepresented in the sample and more likely to come from the community hospitals ($\chi^2=4.950$, $p=0.026$). Approximately, three quarters (73 %) were married. On average, participants were 7.8 years (range, 3–17 years) out from their last active cancer treatment. Ninety-four percent reported that they were currently under the care of a primary care physician (PCP). All participants reported having received cancer follow-up care from a cancer specialist (i.e., medical oncologist, surgical oncologist, radiation oncologist; 70 %) and/or a cancer-related specialist (i.e., urologist; 21 %) within the past year. Approximately, one quarter (24 %) of participants reported seeking care from multiple providers, including a PCP (i.e., family physician, general internist, or gynecologist). Of the four potential typologies explored in this analysis, we found that participants fell into only three of the four categories: groups 1 ($n=6$), 2 ($n=12$), and 3 ($n=15$) (see Table 3).

Group 1: low-activated patients with modest follow-up understanding and limited resources

All participants who were categorized in group 1 were African-American. Half were women and all

Table 1 | Participant demographics (N=33)

	Cancer centers (n=15)		Community hospitals (n=18)		Total (N=33)	
	N or mean	Percent or range	N or mean	Percent or range	N or mean	Percent or range
Race/ethnicity ^a						
White	13	87	9	50	22	67
Black	2	13	9	50	11	33
Age (mean, range)						
<65	8	53	10	56	18	54
65+	7	47	8	44	15	46
Education ^b						
Less than high school	0	0	1	5	1	3
High school–some college	6	40	10	57	16	49
College or more	9	60	6	33	15	46
Marital status (married/cohabiting)						
Currently employed (yes)	9	60	8	44	17	52
Household income						
<20,000	0	0	3	16	3	9
20,000–59,000	4	27	7	39	11	33
60,000–99,000	5	33	3	16	8	24
100,000+	6	40	5	28	11	33
Cancer type						
Breast	6	40	10	56	16	49
Prostate	9	60	8	44	17	51
Years from active treatment						
2–5	6	40	6	33	12	37
6–9	4	27	7	39	11	33
10+	5	33	5	28	10	30
Self-rating of health						
Excellent or very good	7	47	7	39	14	43
Good	7	47	5	28	12	36
Fair or poor	1	6	6	33	7	21

^a $\chi^2 = 4.950$, $df=1$, $p=0.026$

^b Percents do not add to 100 % due to nonresponse

were treated in community hospital settings. Most were long-term survivors with only one man reporting that his last active treatment was <5 years ago. Average annual household incomes for participants in this group were below \$80,000, with most participants reporting household incomes of <\$40,000 ($n=4$) in contrast with those from \$40,000 to \$80,000 ($n=2$).

Participants in this group reported being largely unprepared for follow-up. For example, one survivor responded to the question, “how do you feel about the quality of the cancer follow-up care that you’ve received?”

Um, I don’t know. It’s just that my urologist, he’s good. It’s just a constant, constant going back. The needles, and every time I ask him, one of the things that he always tells me, “Well I’m keeping you alive, ain’t I?” So I keep my mouth shut and drop my pants. But no, I have no real qualms about any of the follow-up care. I guess it’s been necessary. I don’t question it too much. As long as I’m feeling alright” (interview no. 17).

Participants reported that they did not have much knowledge about cancer follow-up care as they did not discuss follow-up care with various members of the health care team (i.e., cancer specialists, medical oncologists, surgical oncologists, radiation oncologists, urologists) or primary care at the end of their active treatment. In addition, their ongoing long-term experiences with follow-up suggest that they received little additional information about what to expect for follow-up. Therefore, they had little frame of reference for understanding what to expect for cancer follow-up care. For example, while data suggest that certain cancer treatments increase patients’ exposure to cardiovascular late effects, one participant noted, “I don’t know if once you have cancer ... is this one of those things that my heart could eventually just do something funny? Why you keep checking for that? And you know ... why are we even still going through the blood work? Is it all of a sudden just going to turn up in my blood like AIDS does or something after 15 years or something?” (interview no. 6).

Table 2 | Criteria for assigning group membership in typologies

	Little understanding of follow-up care	Detailed understanding of follow-up care
Limited or low patient activation	Group 1	Group 4
	Understanding	Understanding
	Have no frame of reference for understanding follow-up	Understand what to expect as part of follow-up
	Have few skills and limited motivation to seek information and/or build skills to manage their follow-up	Have access to skills and resources but little motivation to seek information and/or build skills to manage their follow-up
	Activation	Activation
	Limited skills and tools to function as decision-making agent	Limited skills and tools to function as decision-making agent
	Top-down relationship with care providers related to follow-up (rely heavily on health care team to tell them what to do)	Top-down relationship with care providers related to follow-up (rely heavily on health care team to tell them what to do)
	Do not believe it is their responsibility to manage their care	Do not believe it is their responsibility to manage their care
Expect that things will work out as they should	Expect that things will work out as they should	
High patient activation	Group 2	Group 3
	Understanding	Understanding
	Have no frame of reference for understanding follow-up	Understand what to expect as part of follow-up
	Have moderate/minimal knowledge and skills related to managing their follow-up	Have access to skills and resources and high motivation to seek information and/or build skills to manage their follow-up
	Activation	Activation
	Have goals and a plan to improve their health and manage their follow-up	Have goals and a plan to improve their health and manage their follow-up
	Top-down relationship with care providers related to follow-up (rely heavily on doctors to tell them what to do)	Bidirectional, shared decision-making relationship with care providers related to follow-up
	Understand they should seek care from experts so that their health care providers can tell them what to do	Motivated to seek information and build skills and confidence necessary to manage their follow-up
Initially motivated to seek information and build skills and confidence necessary to manage their follow-up	Believe it is their responsibility to participate in and play an active role in the management of their care	
Can and/or have given up control for monitoring their follow-up to their health care team	Constantly check doctor's opinion and advice on follow-up and other behavioral health care-related issues	

In addition, participants in this group explained that, because they had never been through “something like this before,” they had no experiences with which they could compare cancer follow-up care. Similarly, they also did not know how to measure the quality of their care as they said they had no basis for comparison. A 16-year survivor of breast cancer said, “I really don’t know anything about cancer. ... And [there is] probably somebody better out there; but, I don’t know, because it’s one person I go to all the time. ... Nobody never referred me to nobody else, so I stick with what I get” (interview no. 11).

In terms of patient activation, participants in this group reported low levels of patient activation as operationalized by having limited skills to make decisions about follow-up care seeking and relying heavily on the health care team’s assessment of what to do and when. A 9-year survivor of prostate cancer

stated, “I think [how frequently I need follow-up] needs to be suggested to me by the medical people. Because I don’t want to go more than is necessary. Nor less than necessary. ... If it’s explained to me, I may be able to make a judgment or something like that” (interview no. 13).

Even though participants in this group displayed little activation and did not have many skills that facilitated engagement in shared decision-making regarding their follow-up care activities, they still had expectations that everything would be fine. For example, one prostate cancer survivor, when describing his expectations, said, “What do I expect? Well, being that I don’t know anything about it, you know what I’m saying? As long as somebody was telling me that I’m good, I’m ok, and not—and nothing happened, then I’m still fine, I’m good” (interview no. 44).

Table 3 | Study participants

Participant no.	Race	Age	Annual household income	Cancer type	Treatment location	Years since treatment	Understanding of follow-up	Patient activation
Group 1, low-activated patients with modest follow-up understandings and limited resources, <i>n</i> =6								
6	Black	53	<40,000	Breast	CH	6-9	Limited	Low
11	Black	72	<40,000	Breast	CH	10+	Limited	Low
13	Black	77	<40,000	Prostate	CH	6-9	Limited	Low
17	Black	75	40,000-80,000	Prostate	CH	10+	Limited	Low
30	Black	71	<40,000	Breast	CH	6-9	Limited	Low
36	Black	64	40,000-80,000	Prostate	CH	<5	Limited	Low
Group 2, highly activated patients with modest follow-up understandings and moderate resources, <i>n</i> =12								
7	Black	57	<40,000	Breast	CH	6-9	Limited	High
8	White	62	80,000+	Prostate	CC	<5	Limited	High
9	Black	73	<40,000	Breast	CH	<5	Limited	High
12	Black	56	80,000+	Breast	CC	10+	Limited	High
16	Black	80	40,000-80,000	Prostate	CC	6-9	Limited	High
18	White	73	40,000-80,000	Prostate	CH	10+	Limited	High
20	White	72	80,000+	Prostate	CH	6-9	Limited	High
26	White	73	40,000-80,000	Prostate	CC	10+	Limited	High
31	Black	51	80,000+	Breast	CH	10+	Limited	High
40	White	63	80,000+	Prostate	CH	6-9	Limited	High
41	White	62	40,000-80,000	Prostate	CH	<5	Limited	High
42	White	72	40,000-80,000	Prostate	CC	6-9	Limited	High
Group 3, highly activated patients with detailed follow-up understandings and moderate/high resources, <i>n</i> =15								
1	White	70	40,000-80,000	Prostate	CC	6-9	Limited	High
2	White	58	80,000+	Prostate	CC	<5	High	High
3	White	54	80,000+	Breast	CC	<5	High	High
4	White	66	40,000-80,000	Breast	CC	<5	High	High
10	White	70	40,000-80,000	Breast	CC	10+	High	High
14	White	65	80,000+	Breast	CH	<5	High	High
15	White	59	80,000+	Prostate	CC	<5	High	High
19	White	70	80,000+	Prostate	CH	<5	High	High
24	White	59	80,000+	Prostate	CC	<5	High	High
28	White	47	80,000+	Breast	CC	10+	High	High
29	White	79	40,000-80,000	Prostate	CC	10+	High	High
32	White	56	80,000+	Breast	CH	6-9	High	High
33	White	49	80,000+	Breast	CH	10+	High	High
35	White	60	40,000-80,000	Breast	CH	<5	High	High
43	White	60	80,000+	Prostate	CC	6-9	High	High

CC cancer center, CH community hospital

Group 2: highly activated patients with modest follow-up understandings and moderate resources

Participants in group 2 included both Whites ($n=7$) and African-Americans ($n=5$). Seven were treated in community hospital settings, followed by five at NCI-designated comprehensive cancer settings. Most were long-term survivors, with only three survivors reporting that their last active treatment was <5 years ago. Average annual household incomes for participants in this group were mixed, with five reporting more than \$80,000/year, five reporting \$40,000–80,000, and two reporting household incomes of $< \$40,000$.

Participants in this group told stories that demonstrated that they, like the first group, had a very limited frame of reference for understanding what cancer follow-up care was. For example, one survivor said he did not know what follow-up was, stating, “You know—I’m putting my faith in the doctor, and I know that he has—I feel he has the experience and the expertise” (interview no. 16). Similarly, group 2 participants described top-down relationships with their physicians where they relied heavily on their health care team to tell them what to do and when.

Umm, I’m kind of one of those guys that says, “The doctor knows what he’s doing and if this is what he gives me, this is what he give.” You know? If this is what it is, this is what it is. I don’t, I don’t know, maybe I—I don’t get into it real deeply. I’m assuming that the doctor’s covering everything he needed to cover and, you know—and I don’t know if there’s a whole lot more that he needs to do (interview no. 8).

Unlike group 1 participants, group 2 survivors expressed motivation and the ability to make certain that their treatment and follow-up care needs were being met. They described measures that they took to make certain that they were getting appropriate care. Many described being motivated during their initial treatment to seek information and build the skills and confidence necessary to manage their ongoing follow-up.

I did educate myself—[on] what the implications were and I worked hard to—I started walking right away, as soon as I could, even with the catheter on. And the incontinency thing took care—it’s not like it was. There are certain things you have to be aware of. But as far as not being able to—losing control or anything like that, I got over that real quickly. So that kind of stuff—so they weren’t issues. So I didn’t have to worry about that, so luckily the surgery was successful and there wasn’t a lot of issues so—so I’m not gonna complain about follow-up when I don’t have issues. I’m not gonna look for complaints when there’s no complaints to make. You know what I mean? (interview no. 24).

They also expressed that, because they had done their research ahead of time, they could give up control for monitoring their follow-up to their health care team. One prostate survivor said that he had his sister, who is an operating room nurse, do research to find his treatment team. In his case, he has a PCP that works with his oncologist. “Primary doctor—she keeps an eye, also, on my PSA. And if—and I always ask her how’s the PSA. And tells me it’s fine, and she gives me the readings. And I’m sure if it elevates in any way, she would tell me so. And I would immediately go to my oncologist, which is Dr. B” (interview no. 18). Similarly, another woman said:

Oh, I would like to have a little cheat sheet if I could. Like a bookmark, that would just list for them what they need to do. Um, like I said, go to your primary care, make sure you get your blood work at your primary care. Then I would say go to your, um, oncologist, and then I would list each scan. ‘Cause like I said, I can’t remember them, but I know there are scans. List the scans, with the number of year next to the scan (interview no. 12).

Group 3: highly activated patients with detailed follow-up understandings and moderate–high resources

Participants who were categorized in group 3 were White ($n=15$). Ten were treated in NCI-designated comprehensive cancer center settings and five at community hospital settings. Most reported that their last active treatment was <5 years ago ($n=8$). Average annual household incomes for participants in this group were high, with ten reporting more than \$80,000/year and five reporting \$40,000–80,000.

Participants in this group reported the most defined expectations for follow-up. Many, though not all, discussed follow-up with their health care teams. Most said their cancer treatment teams had prepared them for what to expect in general terms. “[Our conversation about follow-up] was actually fairly general, as opposed to specific. She outlined the number of times that I would continue to see her, talked to me. The only specifics were really in the things that my primary care physician had said that I needed that she disagreed with” (interview no. 14). In addition, most of these participants reported doing extensive research on their own to supplement their doctors’ advice. For example, several described finding information on the Internet and discussing it with their doctors. “[My doctor] knows I access the Internet—she gave me a website where I can pull off the current—I forget the medical organization—their recommended survivor plan” (interview no. 14). They also talk about using information to inform their care team decisions. “I do research online for myself but then I look at it and I think, ‘This isn’t correct,’ so a lot of the stuff you get on the Internet is not correct. I’d rather get it directly from the doctor that you’re seeing. Or, if

you're not satisfied with them, go see another doctor" (interview no. 19).

Yet, even the knowledgeable and activated patients felt that their care was their responsibility and that it was often "disjointed." One long-term survivor of breast cancer summarized, "I have a GP for a check-up. I have an eye doctor. I have a gynecologist. I'm due to get my pap smear. ... yeah, I have doctors to check me out. I have good insurance so I can take care of myself" (interview no. 10).

DISCUSSION

In this study, we explored survivor understandings of follow-up care and motivations and resources for seeking care. Our finding of several different types of survivors with different understanding and skill sets for managing care seeking have important implications for conceptualizing and adding nuance to definitions of the PCMH [18, 20, 22, 38–43] and comprehensive cancer survivor follow-up care, which rely on activated patients as key to their overall efficacy. Through use of typologies, constructed from experiences of patients treated in community oncology and NCI-designated comprehensive cancer centers, we found patient coping styles that ranged from nonactivated patients who need enhanced health care communication and decision support to navigate their care in group 1 to highly activated patients who are adept at navigating complex health care settings in group 3. Our findings suggest that these different types of patients with different care models require PCMH structures that are flexible and can adapt to serve a wide range of patients and their needs.

In their 2011 article, Nutting et al. describe activated patients as central to the PCMH, saying that the "patient-centered" part of the medical home depends on having activated, engaged patients who want better service and transparency in health care and seek to form partnerships with health care practices [22]. These patients need to ask for the care they want and need, when and how they want and need it, as well as for access to information to make appropriate choices [22]. Yet, there is data that suggests that patients' capacities for engaging in shared decision-making in the context of complex chronic disease management is very limited [18].

Groups 1 and 2 remind us that not all patients have either the knowledge and/or skills to advocate for themselves. Patients who are not as knowledgeable and who do not take an active role in their care may lose out when their doctors do not share information with them or when they do not understand the significance of the information that is given. Participants in groups 1 and 2 told us that they did not know what kinds of questions to ask to get the kind of information they wanted. These narratives reinforce the importance of enhancing

survivors' health literacy and/or their ability to obtain, process, and understand basic health information to inform appropriate health decision-making [44–48]. Their stories also emphasize that, without personal or structural resources, these patients are at a disadvantage if they are placed in situations where they need to advocate on their own behalves. Group 1, in particular, reinforces the view that specialized attention needs to be paid to nonactivated patients with fewer resources transitioning from active cancer treatment to follow-up care as their ability to garner resources on their own to fill in gaps in knowledge or expectations about follow-up care is limited. Findings from our current study and previous research suggest that there is a subset of knowledgeable, activated patients who will thrive in PCMH settings. However, we also need to be mindful that there are other patients such as those in groups 1 and 2 who will need access to additional system supports to successfully achieve the care that they need. Therefore, our research, practice, and policy should attend to the needs of moderately and nonactivated patients, as well as the needs of activated patients.

Findings from this study also suggest that it is important to think broadly about how we define and use the PCMH concept when working with cancer survivors and other patients with serious, chronic comorbid conditions. Most articles that discuss the PCMH focus solely on the systemic issues necessary to implement PCMHs in primary care settings. However, the PCMH also needs to be considered in the context of the patient's health care seeking behaviors. Patient engagement [23–25] and the ability to activate patients [26, 27, 49, 50] for continued self-management for cancer follow-up in a chronic disease framework is important. For example, engaging and activating patients by helping them to better understand what their care should consist of and providing patients with care management guidelines and tools to help them to self-monitor may provide a powerful supplement to care guidance provided by health care teams. In addition, PCMHs also need to be considered in relation to other subspecialty care providers. Such a view of the PCMH might benefit from conceptualizing the PCMH in the context of a neighborhood [22, 51] where the patients visit a PCMH that serves as a hub for care that coordinates survivor care seeking among the subspecialty neighbors such as oncologists, surgeons, urologists, gynecologists, mental health specialists, etc. In this—more expanded—view of the PCMH, health care teams would need to use risk appraisals of lifestyle as well as potential late effect and side effect profiles of previous cancer treatments to help guide patient health care seeking behaviors. Care might best be led by physicians or it might be better led by other members of the health care team such as nurse practitioners and physicians assistants. Perhaps, care coordinators and case managers should take a more active role [52].

Currently, there is no research that explicitly assesses which PCMH models of care and care practices will work and for which populations of survivors. This is an area where behavioral findings from practice, policy, and research need to be integrated to inform and enhance care delivery. As this work moves forward, it will need to incorporate opportunities for behavioral training for providers, health care teams, and other members of the PCMH community to achieve patient-centered communication styles that will enhance patients' understandings of their follow-up care needs.

This study has several limitations that should be noted. First, since this was a qualitative pilot study, the racial and ethnic makeup of the sample limits our ability to draw broad conclusions. However, the data are suggestive and indicate directions for further study. Second, our study was not designed specifically to explore the concept of the PCMH. Had we designed the study for this purpose, we would have included patients with a full range of comorbid conditions for whom the PCMH is most needed. Finally, patient understanding of what was communicated to them directly after their active treatment may have been subject to recall bias. All patients in the study were interviewed at least 2 years after their last active cancer treatment. However, given that our focus was on understanding what they currently understood cancer follow-up care to be and how active they currently were in seeking cancer follow-up care, we believe this study is relevant and informative.

Findings from this study highlight that cancer survivors differ in their levels of preparation for, understanding of, and activation to engage in cancer follow-up care. This suggests a need for future research and interventions that include multifaceted patient knowledge and decision support in practice. We believe that examining survivor care in PCMH settings will provide multiple opportunities for enhancing practice, policy, and research to enhance and improve cancer survivorship and follow-up care.

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1. Parry C, Kent EE, Mariotto AB, Alfano CM, Rowland JH. Cancer survivors: a booming population. *Cancer Epidemiol Biomark Prev.* 2011;20:1996-2005.
2. Hewitt ME, Greenfield S, Stovall E, National Cancer Policy Board (U.S.), Committee on Cancer Survivorship: Improving Care and Quality of Life. *From Cancer Patient to Cancer Survivor: Lost in Transition.* Washington, DC: National Academies Press; 2006.

3. Jemal A, Siegel R, Xu J, Ward E. Cancer statistics, 2010. *CA Cancer J Clin.* 2010;60:277-300.
4. Ogle KS, Swanson GM, Woods N, Azzouz F. Cancer and comorbidity: redefining chronic diseases. *Cancer.* 2000;88:653-663.
5. Sunga AY, Eberl MM, Oeffinger KC, Hudson MM, Mahoney MC. Care of cancer survivors. *Am Fam Physician.* 2005;71:699-706.
6. Demark-Wahnefried W, Pinto BM, Gritz ER. Promoting health and physical function among cancer survivors: potential for prevention and questions that remain. *J Clin Oncol.* 2006;24:5125-5131.
7. Baker F, Denniston M, Smith T, West MM. Adult cancer survivors: how are they faring? *Cancer.* 2005;104:2565-2576.
8. Demark-Wahnefried W, Aziz NM, Rowland JH, Pinto BM. Riding the crest of the teachable moment: promoting long-term health after the diagnosis of cancer. *J Clin Oncol.* 2005;23:5814-5830.
9. Kattlove H, Winn RJ. Ongoing care of patients after primary treatment for their cancer. *CA Cancer J Clin.* 2003;53:172-196.
10. Miller DC, Sanda MG, Dunn RL, et al. Long-term outcomes among localized prostate cancer survivors: health-related quality-of-life changes after radical prostatectomy, external radiation, and brachytherapy. *J Clin Oncol.* 2005;23:2772-2780.
11. Wei JT, Dunn RL, Sandler HM, et al. Comprehensive comparison of health-related quality of life after contemporary therapies for localized prostate cancer. *J Clin Oncol.* 2002;20:557-566.
12. Shrader-Bogen CL, Kjellberg JL, McPherson CP, Murray CL. Quality of life and treatment outcomes: prostate carcinoma patients' perspectives after prostatectomy or radiation therapy. *Cancer.* 1997;79:1977-1986.
13. Hewitt ME, Ganz PA, Institute of Medicine (U.S.), American Society of Clinical Oncology (U.S.). *From Cancer Patient to Cancer Survivor: Lost in Transition: An American Society of Clinical Oncology and Institute of Medicine Symposium.* Washington, DC: National Academies Press; 2006.
14. Hudson SV, Chubak J, Coups EJ, et al. Identifying key questions to advance research and practice in cancer survivorship follow-up care: a report from the ASPO Survivorship Interest Group. *Cancer Epidemiol Biomark Prev.* 2009;18:2152-2154.
15. Miller SM, American Psychological Association. *Handbook of Cancer Control and Behavioral Science: A Resource for Researchers, Practitioners, and Policy Makers.* 1st ed. Washington, DC: American Psychological Association; 2009.
16. Oeffinger KC, McCabe MS. Models for delivering survivorship care. *J Clin Oncol.* 2006;24:5117-5124.
17. Arrow K, Auerbach A, Bertko J, et al. Toward a 21st-century health care system: recommendations for health care reform. *Ann Intern Med.* 2009;150:493-495.
18. Scholle SH, Saunders RC, Tirodkar MA, Torda P, Pawlson LG. Patient-centered medical homes in the United States. *J Ambul Care Manag.* 2011;34:20-32.
19. Sia C, Tonniges TF, Osterhus E, Taba S. History of the medical home concept. *Pediatrics.* 2004;113:1473-1478.
20. Wise CG, Alexander JA, Green LA, Cohen GR, Koster CR. Journey toward a patient-centered medical home: readiness for change in primary care practices. *Milbank Q.* 2011;89:399-424.
21. National Committee for Quality Assurance. *NCQA's Patient-Centered Medical Home (PCMH) 2011 Standards and Guidelines.* Retrieved 04/19/2012, 2012 from <http://www.ncqa.org/tabid/631/default.aspx>
22. Nutting PA, Crabtree BF, Miller WL, et al. Transforming physician practices to patient-centered medical homes: lessons from the national demonstration project. *Health Aff (Millwood).* 2011;30:439-445.
23. Gruman J, Rovner MH, French ME, et al. From patient education to patient engagement: implications for the field of patient education. *Patient Educ Couns.* 2010;78:350-356.
24. Institute of Medicine (U.S.), Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century.* Washington, DC: National Academy Press; 2001.
25. Clancy CM. Patient engagement in health care. *Health Serv Res.* 2011;46:389-393.
26. Hibbard JH. Moving toward a more patient-centered health care delivery system. *Health Aff (Millwood).* 2004, *Suppl Variation:* VAR133-135.
27. Hibbard JH, Mahoney E. Toward a theory of patient and consumer activation. *Patient Educ Couns.* 2010;78:377-381.
28. Shapiro CL, McCabe MS, Syrjala KL, et al. The LIVESTRONG Survivorship Center of Excellence Network. *J Cancer Surviv.* 2009;3:4-11.
29. McCabe MS, Jacobs L. Survivorship care: models and programs. *Semin Oncol Nurs.* 2008;24:202-207.
30. Jacobs LA, Palmer SC, Schwartz LA, et al. Adult cancer survivorship: evolution, research, and planning care. *CA Cancer J Clin.* 2009;59:391-410.

31. Hill-Kayser CE, Vachani C, Hampshire MK, Jacobs LA, Metz JM. Utilization of internet-based survivorship care plans by lung cancer survivors. *Clin Lung Cancer*. 2009;10:347-352.
32. Hill-Kayser CE, Vachani C, Hampshire MK, Jacobs LA, Metz JM. An internet tool for creation of cancer survivorship care plans for survivors and health care providers: design, implementation, use and user satisfaction. *J Med Internet Res*. 2009;11:e39.
33. Hudson SV, Miller SM, Hemler J, et al. "Not what I want, but maybe what I need": adult cancer survivor discuss follow-up in primary care. *Annals of Family Medicine*. 2012, in press.
34. Crabtree BF, Miller WL. *Doing Qualitative Research*. 2nd ed. Thousand Oaks, Calif.: Sage Publications; 1999.
35. Denzin NK, Lincoln YS. *Handbook of Qualitative Research*. 2nd ed. Thousand Oaks, Calif.: Sage Publications; 2000.
36. Miles MB, Huberman AM. *Qualitative Data Analysis: An Expanded Sourcebook*. 2nd ed. Thousand Oaks: Sage Publications; 1994.
37. Muhr T. ATLAS.ti. Berlin: Scientific Software Development 2006.
38. Kirchner J, Edlund CN, Henderson K, et al. Using a multi-level approach to implement a primary care mental health (PCMH) program. *Fam Syst Health*. 2010;28:161-174.
39. Nutting PA, Crabtree BF, Miller WL, et al. Journey to the patient-centered medical home: a qualitative analysis of the experiences of practices in the National Demonstration Project. *Ann Fam Med*. 2010;8(Suppl 1):S45-S56. S92.
40. Nutting PA, Crabtree BF, Stewart EE, et al. Effect of facilitation on practice outcomes in the National Demonstration Project model of the patient-centered medical home. *Ann Fam Med*. 2010;8(Suppl 1):S33-S44. S92.
41. Nutting PA, Miller WL, Crabtree BF, et al. Initial lessons from the first national demonstration project on practice transformation to a patient-centered medical home. *Ann Fam Med*. 2009;7:254-260.
42. Richmeier S. Will the real PCMH step forward? *MGMA Connex*. 2011;11:19-20.
43. Sepucha KR, Fowler FJ, Jr., Mulley AG, Jr. Policy support for patient-centered care: the need for measurable improvements in decision quality. *Health Aff (Millwood)*. 2004, Suppl Variation: VAR54-62.
44. Nielsen-Bohlman L, Institute of Medicine (U.S.), Committee on Health Literacy. *Health Literacy: A Prescription to End Confusion*. Washington, DC: National Academies Press; 2004.
45. Hernandez LM, Institute of Medicine (U.S.), Roundtable on Health Literacy. *Health Literacy, eHealth, and Communication: Putting The Consumer First: Workshop Summary*. Washington, DC: National Academies Press; 2009.
46. Wizemann TM, Institute of Medicine (U.S.), Roundtable on Health Literacy, Institute of Medicine (U.S.), Board on Population Health and Public Health Practice. *Health Literacy Implications for Health Care Reform: Workshop Summary*. Washington, DC: National Academies Press; 2011.
47. Institute of Medicine (U.S.), Forum on the Science of Health Care Quality Improvement and Implementation, Chao S, Anderson K, et al. *Toward Health Equity and Patient-Centeredness: Integrating Health Literacy, Disparities Reduction, and Quality Improvement: Workshop Summary*. Washington, DC: National Academies Press; 2009.
48. Zarcadoolas C, Pleasant AF, Greer DS. *Advancing Health Literacy: A Framework for Understanding and Action*. 1st ed. San Francisco, CA: Jossey-Bass; 2006.
49. Hibbard JH, Mahoney ER, Stock R, Tusler M. Do increases in patient activation result in improved self-management behaviors? *Health Serv Res*. 2007;42:1443-1463.
50. Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. *Health Serv Res*. 2005;40:1918-1930.
51. Fisher ES. Building a medical neighborhood for the medical home. *N Engl J Med*. 2008;359:1202-1205.
52. Garrett M. Understanding medical home: a new opportunity for case managers. *Prof Case Manag*. 2009;14:3-4.